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ABSTRACT

This description of the Cedar Valley Hospice program emphasizes palliative and supportive care for terminally ill patients and their families. The history of the hospice movement is outlined along with a description of the Cedar Valley program and the results of a 1980 program evaluation. The appendices contain a statement of the hospice goals and an explanation of standards for a hospice program of care, including: (1) an interpretation of the kinds of care and support available to the patient and the family; (2) the qualifications of the interdisciplinary team; (3) the development of a volunteer staff; and (4) the availability of services regardless of the individual's ability to pay. (JAC)

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THE HOSPICE CONCEPT OF CARE: A FAMILY CENTERED APPROACH

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The Hospice Concept of Care: A Family Centered Approach

by Marilyn Story, Ph.D.

The purpose of Cedar Valley Hospice is to provide palliative and supportive care for terminally ill patients and their families during terminal illness and the following period of bereavement. Emphasis is placed on symptom control, preparation for death, and support before and after death with full scope health services being provided by an organized inter-disciplinary team available on a 24-hours-a-day, 7-days-a-week basis. The inter-disciplinary team always includes a physician, a registered nurse, a social worker or family worker, a clergyman, and a volunteer, all of whom have received special hospice training. Other professionals such as psychologists, occupational therapists, physical therapists, lawyers, etc., may be part of the team. Services of the team help ease the physical, emotional, psyhosocial, and spiritual discomforts attendant to terminal illness and death. The attached goals and standards of Cedar Valley Hospice (see appendix A) list more specifically the needs to be addressed and the services to be offered by this hospice.

Hospice was originally a medieval name for a way station for pilgrims and travelers where they could be replenished, refreshed, and cared for. The name hospice is now used to designate an organized program of care for people going through life's last journey.

In the middle nineteenth century, women of a Catholic order, the Sisters of Charity, originated the idea of hospices for the dying in Ireland, where they often found terminally ill people living and dying alone or found them in rural homes where the family lacked the space, time, energy, and/or skill to care for them properly. First in Dublin and then

elsewhere, these Irish nuns provided clean places where dying persons could be brought for loving care. From Ireland, this work of the Sisters of Charity expanded to England. As the program grew in quality and numbers of persons served, its influence spread to Asia, Africa, and Australia--but without any impact in the United States until the mid-1960's.

Dr. Cicely Saunders, founder and medical director of St. Christopher's Hospice in London (Sydenham), England, helped establish the first United States hospice in 1971 at New Haven, Connecticut. The New Haven Hospice Home Care Program began providing care to patients and their families in March, 1974. A free-standing inpatient hospice facility is now nearing completion in Bradford, Connecticut. Other free-standing inpatient hospice facilities are in operation at Santa Barbara, California; in Marin County, California; at Riverside, New Jersey; and in Paoli, Pennsylvania. Many hospitals, including St. Luke's Hospital in New York City, Royal Victoria Hospital in Montreal, Canada, and Bethesda Lutheran Hospital in St. Paul, Minnesota, have developed units within their walls to give hospice care. Over 250 United States Hospice programs are now in various stages of planning and development in forty-five states plus the District of Columbia.

Cedar Valley Hospice is the first provider of hospice services in northeast Iowa. It is incorporated as a non-profit corporation serving Black Hawk County, Iowa. Cedar Valley Hospice began with an acting board of directors in 1978 and elected a regular board of directors in 1979. The first inter-disciplinary patient care team was trained and ready to begin services to patients and their families in January, 1980. By July 1, 1981, Cedar Valley Hospice had trained five inter-disciplinary patient care teams and was serving 45 patient/family units. Negotiations are currently underway with local hospitals to establish an inpatient hospice unit.

During November, 1980, all team members of the first inter-disciplinary patient care team and patients and patients' family members completed questionnaires and more in-depth interviews evaluating Cedar Valley Hospice. While all gave very positive feedback on the program, team members had some suggestions for improvement. Several stressed the importance of more realistically orienting team members to their roles by having active volunteers speak to teams in training and by having actual patient contact during the team training period. Two team members wanted more training on pain control and one wanted more training on other patient care skills.

Another area cited by several team members was providing more continued support for the inter-disciplinary patient care team. Regularly scheduled time off was seen as important to avoid team member burn-out. Other factors contributing to team support suggested by at least one team member were use of more staffing time to keep in touch with own feelings, more support from a hospice chaplain, a day long seminar periodically to maintain team closeness, and informal get togethers for team members and their families. Cedar Valley Hospice has tried to incorporate these ideas into its continuing program.

CEDAR VALLEY HOSPICE GOALS

The goal of the team will be to help the patient family unit achieve sufficient freedom from the physical and emotional distress of terminal disease so that the patient and family can attain a level of mental and spiritual preparedness for death that is satisfactory for them.

The selection of an appropriate plan of care, and appropriate location for caring, the modification of that care plan and responsive changing needs are the types of decisions which will be made together by the caring team.

After the death of the patient, the Hospice will work with the family through the period of bereavement.

Hospice will work with legislative and reimbursement agencies regarding appropriate and cost effective health care delivery systems for the terminally ill.

STANDARDS FOR A HOSPICE PROGRAM OF CARE

The standards for a Hospice program of care are:

1. The patient and family will be the primary unit of care.

2. Hospice will provide palliative and supportive care for patients with incurable disease and a limited prognosis.

3. Hospice care shall be available twenty-four hours a day, seven days a week to patients and families who have been admitted to a Hospice program.

4. Hospice care to families shall be made available throughout the bereavement period.

5. Hospice care shall be provided by an interdisciplinary team coordinated by a registered and qualified nurse.

6. The medical director of a Hospice program of care shall be a licensed practicing physician.

7. The development and utilization of well trained lay and professional volunteers shall be integral and critical to a Hospice program of care.

8. A Hospice program shall be an autonomous and centrally administrated program of care under the direction of a qualified administrator.

9. Hospice services will be provided on the basis of patient/family need regardless of inability to pay.

10. An accurate and current medical record shall be maintained for every patient/family group receiving Hospice services.

11. Hospice programs shall participate in evaluation, education and research in cooperation with the National Hospice Organization.

STANDARD 1

The patient and family will be the primary unit of care in a Hospice program.

INTERPRETATION

Hospice shall regard the patient to be the person who is in the advanced stages of a cancer and having a limited prognosis in terms of weeks to months.

Hospice shall regard the patient's family to be those persons who have a blood or legal relationship to the patient as well as those persons regarded by the patient as significant though not necessarily legally related.

Hospice shall have as its primary goal to meet the needs of both the patient and the family. Hospice services shall be available on the basis of patient/family need and hospice's ability to provide those services.

STANDARD 2

Hospice will provide palliative and supportive care for patients with incurable disease and a limited prognosis.

INTERPRETATION

Appropriate medical treatment shall consist of application of one of two complimentary concepts of medical care at the correct time in the course of an illness--one concerned with eliminating a controllable disease and the other with relieving the symptoms of incurable cancer. Either must be available when needed. A physician should no more provide aggressive, curative treatment that cannot be effective and that is distressing and isolating, than he should merely control symptoms when there is an underlying cause which is still treatable or has again become treatable.

The primary purpose of a hospice shall be to provide appropriate care for patients with a prognosis of six months or less due to incurable cancer. A major concern of hospice care will be to control signs and symptoms which are causing distress by interfering with the achievement of a satisfactory quality of life. Even if the disease cannot be controlled, a major effort will be made to modify signs and symptoms caused by that disease.

Such a focus of concern recognizes the fact that all elements of a person's existence are relevant. Physical, intellectual, emotional, social, spiritual, and economic stress can both cause and reflect pain, suffering and distress. Helping patients and families cope with these stresses by appropriate application of the various skills of the interdisciplinary team (medical, social work, spiritual, nursing, personal, etc.) will be the antithesis of the tendency to abandon hope and help when only curative endeavors alone are available, and expands the concept of supportive care beyond the purely psychological into a community of caring for the whole person.

STANDARD 3

Hospice care shall be available twenty-four hours a day, seven days a week to patients and families who have been admitted to a Hospice program.

INTERPRETATION

Because hospice care is intended to be flexible to meet the varying needs of the patient/family unit, the hospice program shall make provision to have the full range of hospice service available to every hospice patient/family unit when those needs arise.

It should be noted that hospice care has two components, namely home care and inpatient care. The delivery of hospice home care is intermittent and should be accomplished both by regularly scheduled visits and by provision for the delivery of needed services on an on-call basis. Should inpatient care become necessary, the hospice team will be available at the request of the attending physician.

STANDARD 4

Hospice care to families shall be made available throughout the bereavement period.

INTERPRETATION

The continuum of care provided in a hospice program shall not be completed at the death of the patient. The team shall continue to respond to the family's needs (physical, emotional, spiritual, social, and economic) throughout the grieving process. Attention to bereavement should begin before the patient's death since anticipatory grief is also part of both patient and family life. There are a variety of appropriate grief programs through which this care may be implemented, based on individual hospice's creative response.

STANDARD 5

Hospice care shall be provided by an interdisciplinary team coordinated by a registered and qualified nurse.

INTERPRETATION

The team shall be directed by a physician and coordinated by the hospice nurse taking responsibility for family and patient. The core hospice team shall be composed of the following qualified staff: patient/family, attending physician, hospice physician, patient care coordinator, nurse, mental health specialist, social worker, chaplain, volunteers, and any special service personnel that the team deems necessary.

The hospice team concept is the over-lapping of many systems, and this is what makes hospice care unique. It is a social work system, a nursing system, a medical system, a ministry system . . . all those things at the same time. Just as the chaplain is part of the nursing system, the doctor is part of the spiritual ministry system, and the volunteer part of the social work system, so they all are part of the team which is anxious to give a total hospice care to the family/patient unit.

The team shall accomplish their assigned tasks by the acceptance of appropriate referrals and making clear the professional, medical and nursing responsibilities in cooperation with the attending physician, other involved agencies and the patient/family unit. Appropriate care plan shall be developed which will emphasize all areas of responsibility within a partnership of equals. This shall be accomplished by regular and frequent review of the care, enhancing an open and clear communication which is necessary for excellent care of patient/family.

STANDARD 6

The medical director of a Hospice program of care shall be a licensed practicing physician.

INTERPRETATION

The hospice physician shall be a licensed physician who understands principals and practices of palliative care. He'll need to effectively related to the patient and family and to their attending physicians and the professional community, so as to integrate his special skills with theirs. His own special skills will include expertise in symptom management, especially pain control, and an awareness of the psychological impact of terminal disease and total loss on the patient and the family. He will need to integrate his special skills with the other elements of the hospice interdisciplinary team so that the care program works as a whole. In addition, he should have ready access to consultation in other areas of medical and surgical and paramedical expertise which are in the community.

The degree of direct involvement by the hospice physician in any one patient's care will be determined in cooperation with the attending physician for that patient and the patient/family unit.

STANDARD 7

The development and utilization of a core of well trained lay and professional volunteers shall be integral and critical to a successful hospice program of care.

INTERPRETATION

The volunteer group shall constitute an important interface with community, and provide a pool of persons with time, talent, variety of background and dedication to the Hospice concept.

Volunteers shall serve as back-up support to paid staff in administrative, organizational and operational details of the program as well as in direct service to patient/family.

STANDARD 8

A Hospice program shall be an autonomous and centrally administrated program of care under the direction of a qualified administrator.

INTERPRETATION

To ensure adherence to Hospice standards, it is important that the medical direction, direct services, fiscal management, and program evaluation be centrally administered. Central administration of the above is a means of quality assurance and control of a Hospice program. Autonomy is in relation to other existing forms of health service administration. A Hospice program shall be free to operate under its own policies and procedures lest it be compromised by administrative methodologies not specifically developed to ensure or provide a Hospice program of care.

STANDARD 9

Hospice services will be provided on the basis of patient/family need regardless of inability to pay.

INTERPRETATION

There should not be distinction in quality of services for individual patients. No distinction will be made if a patient cannot pay or if payment is of a particular kind. Hospice may control the number of patients according to staff limitation to care properly.

STANDARD 10

An accurate and current medical record shall be maintained for every patient/family group receiving Hospice services.

INTERPRETATION

A conscientious, up to date, interdisciplinary record of care being given and patient's family's status will be kept. Its purpose will be to provide for better patient care by being a vehicle for interdisciplinary care team communication and coordination as well as being a means of accumulating data for later use in evaluating terminal care in general.

STANDARD 11

Hospice programs shall participate in evaluation, education and research in cooperation with the National Hospice Organization.

INTERPRETATION

Each hospice shall provide and receive from the National Hospice Organization information each shall accumulate regarding hospice care of the terminally ill so that the overall quality of care shall be continuously improved. This information shall be disseminated to providers of such care. Statistics of the Cedar Valley Hospice will be provided to the National Hospice Organization for their use in research. Strict patient confidentiality shall be maintained.